

5-15-2013

A trip to the epilepsy monitoring unit : using video modeling to prepare children and caregivers for inpatient EEG monitoring

Peyton Katz

Bank Street College of Education

Follow this and additional works at: <http://educate.bankstreet.edu/independent-studies>



Part of the [Mental and Social Health Commons](#), and the [Pediatrics Commons](#)

Recommended Citation

Katz, P. (2013). A trip to the epilepsy monitoring unit : using video modeling to prepare children and caregivers for inpatient EEG monitoring. *New York : Bank Street College of Education*. Retrieved from <http://educate.bankstreet.edu/independent-studies/124>

This Thesis is brought to you for free and open access by Educate. It has been accepted for inclusion in Graduate Student Independent Studies by an authorized administrator of Educate. For more information, please contact kfreda@bankstreet.edu.

**A Trip to the Epilepsy Monitoring Unit:
Using Video Modeling to Prepare Children and Caregivers
For Inpatient EEG Monitoring
By
Peyton Katz**

**Mentor:
Troy Pinkney-Ragsdale**

Submitted in partial fulfillment of the requirements of the degree of

Masters of Science

Bank Street College of Education

2013

Abstract

A Trip to the Epilepsy Monitoring Unit

By Peyton Katz

The psychological preparation of children prior to a hospitalization or medical procedure have positive effects on not only a child's admission but also his or her ability to cope following the medical experience. Most children scheduled to undergo inpatient video electroencephalography (EEG) monitoring have pre-scheduled admissions and, thus, have time to psychologically prepare for the experience. Some patients are referred for inpatient monitoring in order to determine whether behaviors a child has been exhibiting are due to epilepsy or a seizure disorder. Others already have a diagnosis of epilepsy or a seizure disorder and are admitted to have their medications adjusted. A number of patients admitted to the epilepsy monitoring unit also have a previous diagnosis of an autism spectrum disorder (ASD) while others are admitted for monitoring to potentially rule out one of these diagnoses. Preparation through video modeling has been previously found to produce positive effects when utilized with both typically developing children as well as those diagnosed with ASDs. Research has shown that exposure to video modeling as a preparation modality can result in reduced stress and anxiety for both patients and caregivers as well as a decrease in patients' disruptive behaviors following admission. Subsequently, with the population of the epilepsy monitoring unit in mind, a video was designed to be placed on the hospital's website in order to support patients and their caregivers as they prepare for their upcoming video EEG and hospital admission.

Table of Contents

Rationale	4
Epilepsy Monitoring Unit and Video EEG	7
Family-Centered Care	10
Psychological Preparation	12
Sensory Preparation	18
Video Modeling as a Preparation Modality	20
Project Development and Application	24
References	27
Appendices: Original Work	
Appendix A: Script: English	32
Appendix B: Script: Spanish	37
Appendix C: Preparation Book for iPad: English	42
Appendix D: Preparation Book for iPad: Spanish	65
Appendix E: Tool for Interactive Play Preparation	88
Appendix F: Consent & Release Letter and Form	89

Rationale

For children and families scheduled to participate in a video electroencephalography (EEG) study, the upcoming experience is fraught with unknowns and can cause stress and anxiety for both the patient and his or her family. Because these admissions are often pre-scheduled, however, there is sufficient time for patients and families to psychologically prepare for their visit if provided with appropriate resources. The psychological preparation of children for hospital admissions and medical procedures is often associated with reducing the stress of these experiences for patients and families, enough so that the American Academy of Pediatrics specifically recommends that children receive preparation services (Committee on Hospital Care, 1970, as cited in Azarnoff & Woody, 1981). The Child Life Competencies, produced by the Child Life Council, outline that it is within the role of the child life specialist to “provide teaching, specific to the population served, including psychological preparation for potentially stressful experiences, with infants, children youth and families” (Child Life Council, 2010, p. 3). Thus, the opportunity for and modality of this preparation is often determined and administered by a hospital unit’s child life specialist.

The use of video as a preparation tool was initially explored because of the ease with which patients and families would be able to access the information on the hospital’s website and the ability they would have to watch it as often as they wish. This idea was supported by research, which spoke heavily to the benefits of children witnessing others role modeling behaviors on film, including a reduction in fear and anxiety in both patients and their parents. In her review of literature investigating the use of video to provide information to patients, Gagliano (1988) discusses that the role modeling of

behaviors on film can be compared to social learning theory's use of live role modeling as a method to decrease participants' anxiety and distress. Her examination of studies concluded that witnessing video modeling could result in decreased anxiety and pain, as well as increased knowledge, cooperation and coping capacity. In her review, Gagliano (1988) determined that, for pediatric patients, role modeling is a "strength" of video preparation. Further exploration also exposed the benefits of utilizing role modeling and video-based interventions with children diagnosed with autism spectrum disorders, a population that makes up a large proportion of patients at the epilepsy monitoring unit of the hospital for which the video was to be created.

The goal of this project was to outline the benefits of utilizing video modeling in the preparation of children and families within a child life department's preparation program. General information on video EEGs exist on the Internet, although the processes depicted on these sites are not necessarily the same as those used in this hospital. Current practice on the epilepsy monitoring unit at this hospital is that verbal instructions for the upcoming hospitalization are provided prior to admission by the unit's social worker via a telephone call to caregivers. The option is also available for an individualized preparation book to be created for the patient by the unit's child life specialist. The research obtained, combined with information from the individual hospital to which the video will belong, was used to develop a comprehensive preparation program for patients admitted to the epilepsy monitoring unit. Prior to their admission, patients and caregivers will be guided to a video on the hospital's website in which a child models what a patient will experience in the hospital. The video will also reinforce the information the social worker discusses with caregivers during their phone

conversation. During their admission, but prior to their hook-up to the EEG equipment, patients will be provided the opportunity to reinforce the sensory experiences and coping techniques introduced by the video using a follow-up electronic preparation book and an interactive play tool. Respecting the diverse population of which the unit serves, again congruent with the competencies put forth by the Child Life Council (2010), Spanish language translations were also created and are included in this guide. Though the information included in the video and follow-up preparation book pertains specifically to the epilepsy monitoring unit for which it was made, these resources can be easily adapted to speak to the practices employed for video EEGs at other institutions.

Epilepsy Monitoring Unit

The goal of a child's admission to the epilepsy monitoring unit is to be able to monitor children as they participate in their normal routine, including while they sleep. Through monitoring, the multidisciplinary team hopes to capture the episodes or behaviors of concern on camera and correlate them to the child's brain activity. In order for this evaluation to occur, the child must have electrodes applied to his or her scalp by an EEG technician. The process of applying the electrodes often takes between forty-five minutes and an hour, during which time the child must be lying down and in a still position. The application process begins with a systematic measuring of the child's head, during which time markings are made as to where electrodes should be placed. The technician then applies the electrodes, connected to wires, to the child's head using medical glue. After each electrode is in position, the technician applies a piece of gauze, upon which he or she then blows medical air in order to harden the glue. Once all of the electrodes are placed, the technician wraps the child's head with a large piece of gauze in order to hold the electrodes in place. The electrodes and their corresponding wires are then attached with cables to a monitor in the patient's room.

Children can be referred for inpatient monitoring for a variety of reasons. Some patients have already been diagnosed with epilepsy or a seizure disorder and need to be observed for medication maintenance, while others are referred to see if behaviors a child has been exhibiting are in fact seizures. A number of patients admitted to the unit also have a previous diagnosis of an autism spectrum disorder or are displaying behaviors congruent with these conditions. Autism spectrum disorders (ASDs) refer to a group of developmental disabilities listed in the *Diagnostic and Statistical Manual of Mental*

Disorders, Fourth Edition, including autistic disorder, pervasive developmental disorder-not otherwise specified, Asperger syndrome, Rett syndrome and childhood disintegrative disorder (Mirenda & Iacono, 2009).^{*} Those diagnosed with an ASD might face challenges in communicating with others, participating in social interactions and partaking in daily activities (Autism Speaks, 2011). Another distinguishing feature of ASDs is the tendency to experience “sensory overload,” resulting in perceived intensity of stimuli such as light, sounds and smells (Autism Speaks, 2011, p. 3). The modulation of stimuli might be increasingly difficult for children in the hospital, a setting characteristically marked by bright lights, loud noises and strong smells. The EEG hook-up process, specifically, can present a challenge for those with difficulty integrating sensations related to touch, smell and sound.

Some patients with a previous diagnosis of an ASD admitted to the epilepsy monitoring unit are believed to be experiencing seizures or have already been diagnosed with epilepsy. According to Tuchman and Rosanoff (2011) between twenty and forty percent of those with autism spectrum disorders also have epilepsy. However, in addition to those who already have a diagnosis of an ASD, many children are admitted and monitored in order to determine if behaviors they are experiencing are the result of an ASD or a seizure disorder. In these circumstances, testing requires a minimum of a two-night stay in the hospital. One type of monitoring and interpretation the medical team can perform during this time is to investigate whether electrical status epilepticus in sleep (ESES) is occurring, which means that sleep spike wave status is observed while a child is sleeping. This finding often supports a diagnosis of Landau-Kleffner syndrome. This

^{*} The fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)* is scheduled to be released in May 2013. The new edition is expected to have a different characterization of autism spectrum disorders than the fourth edition. As the *DSM-5* publication date is after the submission of this project, it is recommended that readers review the latest *DSM* for the most up-to-date information.

condition might account for the language and behavior regressions that often accompany a diagnosis of an ASD. Therefore, some doctors choose to rule out Landau-Kleffner syndrome before diagnosing an ASD, and thus these children are referred for inpatient monitoring.

Family-Centered Care

Family-centered care practices, which focus on the importance of “supporting and encouraging” families in the process of a child’s hospitalization, have become a standard in many institutions including the hospital behind this project (Thompson, 2009, p. 98). The United States Department of Health and Human Services released two publications in recent years that made family-centered care the benchmark for the care of children with special healthcare needs (US Department of Health and Human Services Maternal and Child Health Bureau, as cited in Thompson, 2009). In addition to respecting individual families and helping preserve parents’ natural roles as their child’s caretakers, instituting family-centered care can result in a variety of benefits for patients, families and the institutions themselves. For example, it has been found that implementing family-centered care can result in “improvement in medical and developmental outcomes;...enhanced patient and family satisfaction and staff and faculty satisfaction as well; wiser use of scarce resources, with a reduction in healthcare costs;” and “enhanced competitiveness for the hospital in the marketplace” (Johnson, 2001, as cited in Thompson, 2009).

The incorporation of family-centered care practices in the epilepsy monitoring unit is especially applicable as caregiver involvement and support play a vital role in the success of EEG monitoring. Not only might patients benefit from the supportive presence of their caregiver, but caregivers are also seen as valuable members of the team in achieving meaningful monitoring. Caregivers are assigned a number of responsibilities during a child’s admission, including supporting their child through the hook-up process and alerting the staff when they witness one of their child’s seizures or

events. Because of their expected involvement in the process, the created preparation video seeks to help prepare not only children but also their parents or caregivers for the upcoming procedure.

Psychological Preparation

Patients who undergo psychological preparation prior to medical experiences have been found to experience a number of positive benefits, including reductions in stress, fear and anxiety. The reduction of these emotions can directly impact the EEG hook-up process. According to Benore and Enlow (2013), “procedural anxiety and behavioral distress in children can interfere with EEG results, lead to prolonged EEG studies and increase the risk of conditioned fear to medical procedures in children.” Since 1965, studies have repeatedly found that the most significant factors in effective preparation are “the provision of developmentally appropriate information, the encouragement of emotional expression and the formation of a trusting relationship with a health care professional” (Koller, 2007, p. 4).

From 1985 to 1987, the Association for the Care of Children’s Health (ACCH) implemented a research-based program child life program at Phoenix Children’s Hospital with the goal of assessing the value of child life services (Gaynard et al., 1990). Guidelines were established using information obtained from this study as to how child life specialists should prepare children and families for health care experiences. Sixteen standards were established, regarding, among others, using “minimally threatening, age-appropriate language,” providing “accurate information about what the child will actually experience” and offering “opportunity for rehearsing effective coping behaviors” (Gaynard et al., 1990, p. 95).

In 2006, the American Academy of Pediatrics (AAP) released a policy on child life that discusses child life specialists’ use of psychological preparation as a tool that helps “facilitate coping and adjustment at times and under circumstances that might prove

overwhelming otherwise.” The policy states that, through preprocedural preparation, child life specialists are able to address patients’ possible misconceptions about what they are going to experience. It also discusses that such preparation helps to “make the unpredictable events more manageable” and provides children the opportunity to “plan and rehearse coping strategies” (AAP, 2006). The AAP (2006) also outlines potential benefits of preparation for parents and caregivers in the hospital setting, stating that preprocedure preparation can not only “enhance the parent’s ability to support the child,” but can also “contribute to a parent’s ability to cope more effectively, often resulting in greater cooperation and success during the procedure.”

The American Heart Association, in their Scientific Statement entitled “Recommendations for Preparing Children and Adolescents for Invasive Cardiac Procedures,” further outline how staff can help to reduce the need for pain and anxiety management medications and reduce the stress associated with hospitalizations and procedures using consistent preprocedural preparation. Based on a review of literature and expert consensus, the authors emphasize that by receiving information about an upcoming procedure children might be better able to understand the reason and meaning for the procedure or hospitalization (Leroy et al., 2003). They also explain that preparation can allow patients and families to perceive a sense of mastery in the situation since they may be able to anticipate what will occur during the procedure (Leroy et al., 2003). Through accurately understanding what will occur and why some of the unknown aspects of medical experiences are removed, thus potentially reducing fear and anxiety.

In one of the only published studies to date on the effects of preparation on EEG compliance, Benore and Enlow (2013) explored the use of psychoeducation and distraction during outpatient EEG visits. One hundred and thirty-nine children between the ages of 0 and 6-years-old and their caregivers were divided into two conditions: the control group received basic instructions and information about the procedure itself while the experimental group received a brochure that gave suggestions on how parents could psychologically prepare their children for the EEG. Those children and caretakers in the experimental group were then shown a 5-minute video upon admission to the unit, which provided both psychoeducation and modeled distraction behaviors that parents could implement during the procedure. A numerical rating scale completed by both parents and EEG technicians was used to assess, on a scale of 1 to 100, both parental and patient procedural anxiety prior to the EEG. Parents were also asked to complete the State-Trait Anxiety Inventory for Adults Results. Patients' behavioral distress was assessed during the setup of the procedure and the EEG recording using the FLACC scale, a behavioral pain assessment scale based on observational ratings. A noise dosimeter was also utilized to measure and record any distress vocalizations, such as crying or screaming, made by the patient during the procedure. Afterwards, parents were also asked to report on their experience and satisfaction with the EEG procedure. Results showed that parents in the experimental group demonstrated significantly less anxiety than those in the control group, especially those whose children were infants. These parents also reported feeling more prepared and less distressed. The research found no difference in demonstrated child or infant anxiety, however vocalized distress was less intense and of less duration for those children in the experimental group. It was also discovered that education about

distraction methods did not subsequently increase the amount of time required for the EEG hook-up.

In addition to reduced fear and anxiety at the time of the procedure, research has found that preparation can continue to positively affect children throughout their hospitalizations and after their discharges. For example, Visintainer and Wolfer (1975) compared the effects of exposing children between 3 and 12-years old scheduled to receive tonsillectomies to either preparation at six determined stress-points of the hospitalization, preparation during a single session, consistent supportive care, or a control condition which included no systematic preparation. The researchers hypothesized that the stress-points condition would most promote child and family adjustment to the hospitalization. The findings for the stress-point preparation compared to single-session preparation were not as clear as the hypothesis anticipated they might be. However, the results showed that the systematic preparation and support included in the first two experimental conditions were associated with an “increase children’s cooperation, decreased their upset behavior and problems in posthospital adjustment” as well as “less anxiety, better information, and more satisfaction with care for their parents” (Visintainer & Wolfer, 1975, p. 199). Findings on children’s cooperation following preparation are specifically relevant to the process of an EEG hook-up. Increased cooperation could help the process occur more successfully and be less traumatic as it might take less time and the child may not need additional restraint.

Like Benore and Enlow, Visintainer and Wolfer (1975) also found that preparation before pediatric procedures can have positive effects on parents. Specifically, they found a significant reduction in parental anxiety and an increase in

parental satisfaction following preparation (Visintainer and Wolfer, 1975). This is noteworthy as parental anxiety has been found to have an effect on a child's perception of anxiety (Koller, 2007). Therefore, by including parents in preparation services, it is possible to further reduce a child's anxiety by association.

The benefits of preparation for procedures have also been found to extend beyond a child's admission. As cited above, Visintainer and Wolfer (1975) found that children who received preparation reported significant ease of adjustment after leaving the hospital. Preparation can also promote a child's ability for continued coping to future health care situations (Koller, 2007). Long-term consequences of negative medical experiences can be "profound," including post-traumatic stress and increased fear (Koller, 2007). Preparation, however, has been found to limit the traumatic effects of hospitalizations (Azarnoff & Woody, 1981).

The potential benefits of procedural preparation in the epilepsy monitoring unit are further confounded when it is noted that children diagnosed with ASDs have been found to have a high prevalence of specific fears, including those related to medical experiences (Gillis, Natoff, Locksin & Romanczyk, 2009). In an assessment of reported fears of children and adolescents with developmental delays compared to those of typically developing peers, the fear of going to the hospital was a top fear for those with developmental disabilities that was not similarly cited by the comparison group (Knapp, Barrett, Groden & Groden, 1992, as cited in Gillis et al., 2009).

The effects of preparing patients and families for medical experiences also extend to the hospital as an institution. According to Pinto and Hollandsworth (1989), preparation can reduce both "individual and overall medical costs." In a study by Hatava,

Olsson and Lagerkranser (2000) looking at patients' and parents' responses to preparation services before ENT surgeries, parents reported not only lowered anxiety but also greater satisfaction when they were exposed to preparation services. Visintainer and Wolfer (1973) reported similar findings. As patients' reported perceptions of care become more widely accessible through the national implementation of Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS), the importance of improving patient satisfaction will likely become an increasingly influential goal for hospitals. Because reported data from HCAHPS will be publically available, its findings could affect prospective patients' choice of hospital. As such, the preparation of children and families for procedures is a method hospitals might choose to implement in order to increase patient satisfaction, which can positively affect the hospital's HCAHPS scores.

Sensory Preparation

In designing a preparation program, it is important to consider and relay how medical experiences might involve children's senses. The guidelines on preparation established following the research study at Phoenix Children's Hospital emphasize the need to describe the sensory experiences a child might have in the hospital or during a procedure (Gaynard et al., 1990). An analysis of studies including sensory and procedural preparation revealed that the children in each of these studies experienced reduced negative emotions (Koller, 2007). The need for sensory preparation for an EEG is further supported when it is considered that, in conversations with staff at the hospital for which this project was created, the most apparent difficulty for many patients are the sensory components to the EEG hook-up. Preparation might include discussions about what a child might see, hear, smell, taste or feel during a procedure. For children being admitted to the epilepsy monitoring unit, for example, preparation should include discussion of the smell of the glue and the sound and feeling of the air drier, among others.

The necessity of sensory preparation is further supported when it is considered that ASDs are often marked by sensory processing difficulties (Baranek et al., 2006). According to Carol Stock Kranowitz (2005), author of *The Out-of-Sync Child*, "problems with sensations...are among the main areas of impairment" for those with autism (p. 32). Baranek et al. (2006) developed and administered a sensory experiences questionnaire to caregivers of 258 children ages 5 to 80-months-old in five diagnostic groups, including autism, PDD, developmental disabilities/mental retardation, other developmental disabilities, and a typically developing control group. The researchers found that those in

the group with autism diagnoses reported a 69% prevalence of overall sensory symptoms relative to means of the data reported for typically developing children. Children with autism were found to exhibit higher levels of hyporesponsiveness than children in the other groups. However, hyperresponsiveness to sensations was similarly recorded for those in the groups with autism and both groups comprised of children with developmental delays. The hyperresponsiveness of both of these groups, however, was significantly greater than that reported of the control group. It was also found that within the control group parents of younger and less mature children reported hyperresponsiveness to novel stimuli. Thus, as much as all children benefit from sensory descriptions during preparation services, patients with ASDs and younger typically developing children might benefit from increased opportunity for exposure to sensory stimuli in order to address the challenging time these children often have adjusting to sensory information.

Video Modeling as a Preparation Modality

Because patients admitted to the epilepsy monitoring unit often know in advance about their admission, it is important to consider how this time could best be utilized to provide appropriate preparation. An examination of published literature indicates that video preparation is a valuable tool in preparing both patients and parents for procedures and hospital admissions. Although much of the literature is restricted to studies utilizing video preparation for anesthesia induction or day surgery procedures, it can be reasoned that the benefits would be similar for patients with planned admissions for other departments.

In an examination of pre-procedural preparation modalities, Ferguson (1979) sought to compare the effects of exposing children between the ages of 3 and 7-years-old scheduled for tonsillectomies to either a preadmission visit by a nurse or a peer modeled video. A control group that received neither intervention was also included. Patients' anxiety was measured via self-report, biological measures of muscular tension and ratings of behavioral distress. Vernon et al.'s Post-Hospital Behavior Inventory was used to evaluate post-hospital adjustment. Parental responses were assessed using self-report of anxiety and satisfaction. Though it was found that maternal anxiety was reduced by the preadmission visit, children who viewed the peer modeled film were reported to experience a decrease in hospital-specific physiological anxiety and a lowered incidence of undesirable behavior following the hospitalization.

Melamed and Siegel (1975) were interested in determining whether the discovered benefits of video preparation were due to the content of the video or that children merely enjoyed watching videos in general. Sixty patients admitted for elective

surgeries were shown either a peer modeled film of another child's hospitalization or a control film unrelated to the hospital participants. Results showed a reduction in both preoperative and postoperative anxiety measures in patients who viewed the peer modeled film. Like Fergusson, Melamed and Siegel (1975) also found that parents of patients exposed to video modeling prior to their hospitalizations reported a significant reduction in undesirable behaviors when children were exposed to a peer modeled film before surgery.

A similar study by Melamed, Yurcheson, Fleece, Hutcherson and Hawes (1978) sought to compare the effects of exposing children to either a peer modeled video or one that merely demonstrated the upcoming procedure. Participants in this study were between the ages of 4 and 11-years-old and were scheduled to receive dental procedures. The researchers found "those who viewed a peer-model videotape immediately preceding their own treatment exhibited fewer disruptive behaviors and reported less apprehension than those watching a demonstration without a peer model" (Melamed et al., 1978).

In developing a video, it is necessary not only to consider who models the behavior but also who narrates the actions occurring. The only study found to look specifically at this issue was conducted by Pinto and Hollandsworth. In this study, the researchers exposed 60 pediatric patients receiving first-time elective surgery to one of two groups, in which they would see a video either with or without their parents present (Pinto & Hollandsworth, 1989). Within these groups there were three treatment conditions: an adult-narrated film, a peer-narrated film and a control group that did not receive video preparation. Anxiety was measured using biological indicators of stress, self-reported levels of procedural anxiety, an observer rating of anxiety and behavioral

measures of the patient's recovery. Patients in both videotape conditions self-reported and displayed less anxiety compared with those children who did not view a video. Children who viewed the film with their parents "exhibited less preoperative arousal compared with children who did not" (Pinto & Hollandsworth, 1989). In addition, parents who either viewed the videotape themselves or whose children viewed the tape without them present "exhibited less arousal prior to the operation than parents who did not and whose children did not" (Pinto & Hollandsworth, 1989). Having the videotape narration recorded by an adult or peer did not produce significant differences in participant responses, though preliminary analysis suggests that younger children might display less anxiety after viewing an adult-narrated film.

Significant benefits to caregivers who receive video preparation have also been observed and reported. Research shows that viewing this style of preparation prior to their child's procedure can address parents' desire for information (McEwen, Moorthy, Quantock, Rose & Kavanagh, 2007); lower parents' blood pressure (Zuwala, 2001, as cited in Yip, Middleton, Cyna & Carlyle, 2010); promote an increase in knowledge related to the hospitalization or procedure (Cassady, Wysocki, Miller, Cancel & Izenberg, 1999) and significantly reduce parents' anxiety (Cassady et al., 1999; McEwen et al., 2007).

Despite the repeated findings showing benefits of video preparation for pediatric patients, there are opposing viewpoints as to what drives these effects. Pinto and Hollandsworth (1989) found that even when children viewed the video preparation without a parent present they appeared less anxious prior to surgery than those that did not receive preparation. However, a review of previous studies comparing the

effectiveness of media-based patient education about anesthesia conducted by Lee, Chui and Gin (2003) suggests that these interventions help to reduce parents' anxiety but do not affect the patients' own anxiety. Nonetheless, according to the concept that caregiver anxiety can affect children's anxiety, it can be reasoned that this reduction in caregiver anxiety may produce a similar effect in the patient.

Video modeling is also an appropriate preparation modality for use by the epilepsy monitoring unit as it has been successfully used to encourage individual skills in children with ASDs for decades (Wilson, 2013). One reason for this finding might be that those with ASDs have been found to generally "possess relative strengths in visual processing" (Minshew, Goldstein & Siegel, 1997, as cited in Wilson, 2013). Preparation utilizing video recordings is thus an appropriate option for the hospital seeking to prepare all of its patients, independent of coexisting diagnoses, for the same procedure.

Like preparation in general, the positioning of video preparation available on the hospital's website can have positive benefits not only for patients and families but also for the hospital as an institution. Having the video be easily accessible to patients and families can allow for repetitive watching prior to admission, which can further the potential for a perception of mastery by both patients and caregivers. The hospital can benefit from video preparation as it has the potential to reduce the medical costs of treating patients. In their study, Pinto and Hollandsworth (1989) determined that \$7,326.80 was saved in medical costs through the preparation of children for their upcoming procedures. It is also worth considering that online videos are an emerging "effective marketing and patient education tool" that can help users "establish...trust in their doctors" even before entering the hospital (Huang, Bolchini & Jones, 2010).

Project Development and Application

In accordance with the hospital's and child life department's commitment to encouraging family-centered care, a number of caregivers were interviewed in order to both assess caregiver perception of need for the project and receive suggestions as to what they believed would be beneficial to know prior to admission for both themselves and for their children. These caregivers received phone calls by the unit's child life specialist. While every one of the caregivers contacted felt that a video would be helpful, none provided suggestions as to what the video should include. Thus, the majority of information for the video's script was obtained through discussion with interdisciplinary team members who work with patients and families at the epilepsy monitoring unit. These team members included a doctor, nurse, social worker, physician assistant, EEG supervisor and child life specialist. The director of the hospital's child life program worked with the hospital's marketing department in order to arrange for the filming of this video to coincide with filming that was previously scheduled to occur at the hospital. Once the video is created, it will be placed on the hospital's website, staff who speak with families prior to admission will direct them to the video and encourage them to view it. The video will also be available for patients and families to view after their arrival through the hospital's internal video network.

The video will be divided into two sections: one directed towards the patients and one with useful instructions and information for parents and caregivers. The first half of the video will be focused on what a child will experience during his or her first day at the hospital. As a result of Pinto and Hollandsworth's (1989) preliminary findings on the potential benefits of adult-narration, the epilepsy monitoring unit's child life specialist

will provide the narration for this video. Congruent with the research on the benefits of children witnessing others role-modeling behaviors, a patient who has been treated in the past will be shown participating in the actions described during the first half of the video. The second half of the video, which will focus on parents and caregivers, will also be narrated by the child life specialist. In this section, however, she will be shown on the screen. Bullet-points of key topics she discusses will also be displayed.

Following the creation of the video script, it was determined that corresponding iPad slides would also be created as an accompaniment to the video in order to provide the opportunity for the child life specialist to further prepare the patient and address any questions or misconceptions. Patients will be encouraged to explore these preparation slides while waiting for their hook-up to the EEG equipment. The script and slides are designed to use both developmentally appropriate as well as minimally threatening language congruent with the competencies of the Child Life Council (2010). The language utilized for the slides is simple and direct, with the intention that this style will be beneficial for use with younger patients and those patients with special needs. The text on the slides can be easily supplemented with additional conversation for use with any age group. Like the video script, the slides are in both English and Spanish to best provide for the diverse patient population that visits the unit. Audio recordings are also included in both the English and Spanish versions. Above the text on each slide are images depicting what the child will see or experience during the procedure. The slides focus on the EEG hook-up, with extra attention paid to sensory information and the child's role during the procedure. The interactive quality to the iPad slides will allow children the opportunity for choice and control of when to change slides, which can

further cultivate their perception of mastery over their experience. Some believe that children with autism can also significantly benefit from this modality because they are granted the opportunity to control the rate at which they receive the stimuli in their environment (Brandon, 2011).

An interactive tool that provides children the opportunity to gain familiarity and mastery over the materials was also created. Patients will be able to manipulate the electrodes as they place them on four culturally diverse representations of children as they await their own hook-ups. This playful approach will provide patients the opportunity to explore and interact with the materials in a nonthreatening and playful way. This tool could also be used as a tool for postprocedural support to aid in patients' coping and allow them to work through their experience.

Resources

American Academy of Pediatrics (2006). Child life services. *Pediatrics*, 118(4), 1757-1763.

Autism Speaks (2011). Taking the Work Out of Blood Work: Helping Your Child With ASD [PDF document]. Retrieved from <http://kc.vanderbilt.edu/asdbloodwork/pdfs/ParentGuide.pdf>.

Azarnoff, P. & Woody, P. (1981). Preparation of children for hospitalization in acute care hospitals in the United States. *Pediatrics*, 68(3), 361-368.

Baranek, G. T., David, F. J., Poe, M. D., Stone, W. L., & Watson, L. R. (2006). Sensory Experiences Questionnaire: Discriminating sensory features in young children with autism, developmental delays, and typical development. *Journal of Child Psychology and Psychiatry*, 47, p. 591–60.

Benore, E. & Enlow, T. (2013). Improving pediatric compliance with EEG: Decreasing procedural anxiety and behavioral distress. *Epilepsy & Behavior*, 27(1), 169-173. doi: 10.1016/j.yebeh.2013.01.011

Brandon, J. (2011, March 9). Is the iPad a ‘Miracle Device’ for autism? *Foxnews.com*. Retrieved from <http://www.foxnews.com/tech/2011/03/09/can-apple-ipad-cure-autism>.

Cassady J.F., Wysocki, T.T., Miller, K.M., Cancel, D.D., & Izenberg, N. (1999). Use of a preanesthetic video for facilitation of parental education and anxiolysis before pediatric surgery. *Anesthesia & Analgesia*, 88, 237–239.

Child Life Council. (2010). Child life competencies.

- Furguson, B.F. (1979). Preparing Young Children for Hospitalization: A Comparison of Two Methods. *Pediatrics*, 64(5), 656-664.
- Gagliano, M.E. (1988). A Literature Review on the Efficacy of Video in Patient Education. *Journal of Medical Education*, 63(10), 785-792.
- Gaynard, L., Wolfer, J., Goldberger, J., Thompson, T., Redburn, L., & Laidley, L. (1990). *Psychosocial care of children in hospitals: A clinical practice manual*. Maryland: Association for the Care of Children's Health.
- Gillis, J.M., Natoff, T.H., Locksin, S.B., & Romanczyk, R.G. (2009). Fear of routine physical exams in children with autism spectrum disorders: Prevalence and intervention effectiveness. *Focus on autism and other developmental disorders*, 24(3), 156-165.
- Hatava, P., Olsson, G.L., & Lagerkranser, M. (2000). Preoperative psychological preparation for children undergoing ENT operations: A comparison of two methods. *Paediatric Anaesthesia*, 10, 477-486.
- Huang, E., Bolchini, D., & Jones, J.F. (2010) Users' Consumption of Healthcare Videos on Hospital Web Sites [Abstract]. *Proceedings of the Northeast Business & Economics Association*, 411-416.
- Koller, D. (2007). Child life council evidence-based practice statement preparing children and adolescents for medical procedures. Retrieved from <http://www.childlife.org/files/ebppreparationstatement-complete.pdf>.
- Kranowitz, C.S. (2005). *The out-of-sync child: Recognizing and coping with sensory processing disorder*. New York: Penguin Group.

- Lee, A., Chui, P.T., & Gin, T. (2003). Educating patients about anesthesia: a systematic review of randomized controlled trials of media-based interventions. *Anesthesia & Analgesia*, 96(5), 1424-1431.
- LeRoy, S., Elixson, E.M., O'Brien, P., Tong, E., Turpin, S., & Uzark, K. (2003). American Heart Association Pediatric Nursing Subcommittee of the Council on Cardiovascular Nursing; Council on Cardiovascular Diseases of the Young. Recommendations for preparing children and adolescents for invasive cardiac procedures: a statement from the American Heart Association Pediatric Nursing Subcommittee of the Council on Cardiovascular Nursing in collaboration with the Council on Cardiovascular Diseases of the Young. *Circulation*, 108. 2550–2564.
- McEwen, A., Moorthy, C., Quantock, C., Rose, H., & Kavanagh, R. (2007). The effect of videotaped preoperative information on parental anxiety during anesthesia induction for elective pediatric procedures. *Pediatric Anesthesia*, 17(6), 534-539. doi: 10.1111/j.1460-9592.2006.02173.x
- Melamed, B.G. & Siegel, L. (1975). Reduction of anxiety in children facing hospitalization and surgery by use of filmed modeling. *Journal of Consulting and Clinical Psychology*, 43(4), 511-521.
- Melamed, B.G., Yurcheson, R. Fleece, E. L., Hutcherson, S. & Hawes, R. (1978). Effects of film modeling on the reduction of anxiety-related behaviors in individuals varying in level of previous experience in the stress situation. *Journal of Consulting and Clinical Psychology*, 46(6), 1357-1367.
- Miranda, P. & Iacono, T. (2009). *Autism spectrum disorders and AAC*. Baltimore, MD: Paul H Brookes Publishing Co.

- Pinto, R.P. & Hollandsworth, J.G. (1989). Using videotape modeling to prepare children psychologically for surgery: influence of parents and costs versus benefits of providing preparation services [Abstract]. *Health Psychology: Official Journal of the Division of Health Psychology, American Psychological Association*, 8(1), 79-95. doi: 10.1037//0278-6133.8.1.79
- Press Ganey Associates, Inc. (2013). HCAHPS: Press Ganey Hospitals Outperform. Retrieved from <http://www.pressganey.com/researchResources/governmentInitiatives/HCAHPS.aspx>
- Thompson, R. H. (2009). *The handbook of child life: A guide for pediatric psychosocial care*. Springfield, Ill: Charles C. Thomas.
- Tuchman, R. & Rosanoff, M. (2011, August 5) How common are seizures among people with autism, and what can help? [Weblog]. Retrieved from <http://blog.autismspeaks.org/2011/08/05/how-common-are-seizures-among-people-with-autism-and-what-can-help/>
- Wilson, K.P. (2013). Incorporating video modeling into a school-based intervention for students with autism spectrum disorders. *Language, Speech & Hearing Services in Schools*, 44(1), 105-117.
- Visintainer, M.A., & Wolfer, J.A. (1975). Psychological preparation for surgical pediatric patients: The effect on children's and parents' stress responses and adjustment. *Pediatrics*, 56, 187-202.
- Yip, P., Middleton, P., Cyna, A.M., & Carlyle, A.V. (2010). Non-pharmalogical interventions for assisting the induction of anaesthesia in children. *Cochrane*

Database Syst Review. 2009 Jul 8;(3):CD006447. doi:
10.1002/14651858.CD006447.pub2.

Appendix A:

“A Trip to the Epilepsy Monitoring Unit”

ADMISSIONS

You are coming to stay at the hospital so the doctors can learn more about what is happening in your brain. You will be getting something called an EEG –we’ll explain more about the EEG later!

The first stop of your day will be to check-in at the admitting office.

MAIN HOSPITAL

After you finish checking in, you will come over to the children’s hospital building.

EPILEPSY MONITORING UNIT

You will take the elevator up to the 6th floor, where the epilepsy monitoring unit is. When you get off the elevator, you will see the unit secretary. She has lots of important jobs! She will tell you and your family where to go.

While you’re on the 6th floor you will get a wristband that says your name and other important information. You will need to keep this wristband on the whole time you’re at the hospital so that everyone knows who you are.

LOUNGE

You will wait in a lounge area to speak with the nurse, EEG tech, physician assistant or doctor before going to your room. It’s a great idea to bring some activities or snacks to have during this time.

When you meet the doctors, physician assistant and nurses you will be asked questions about any medication you take at home and the seizures or events you’re having so that the hospital staff is better able to prepare for them.

You will also get a complete physical and neurological exam so that the doctors know how healthy you are.

MEETING THE STAFF

These are some of the people who work as a team to take care of you and your family while you are in the hospital.

Attending physician: Each month, a different attending physician is in charge of working with patients in the Epilepsy Monitoring Unit. This doctor will stop by every day to check on you. He or she will tell the rest of the medical team what they are seeing each day.

Residents and fellows: You might also meet doctors called residents or fellows who will help with your admission and take care of you on the weekends.

Physician assistant: The physician assistant works closely with your doctor and nurses to help create a care plan for you each day.

Nurses: The nurses will check in with you throughout the day and make sure that you're comfortable. They will check your temperature and blood pressure and give you any medicine that you take.

Child life specialist: At some point during your hospital stay you will meet someone called a child life specialist. The child life specialist can teach you about the hospital, help you during your EEG hook-up and also bring you lots of fun activities to do while you're in the hospital.

EEG technician: The EEG technician is a person who is trained to get you set-up for your EEG.

Social worker: The social worker will come meet your family and ask questions about your life in order to help create a plan for when you leave the hospital.

Food servers: A group of people who bring you your breakfast, lunch and dinner while you're in the hospital.

Environmental services: You might see someone from environmental services, whose job it is to make sure the hospital is always kept clean.

HOSPITAL ROOM

Now let's go see your room. Either your mom, dad or caregiver will be staying with you while you're in the hospital, even while you're sleeping! This is both for you to feel more comfortable and for them to help us record when you are having a seizure or event. You may have a roommate.

Your nurse will come to meet you in your room. She will check something called your "vital signs." This means she will measure your temperature with a thermometer, see how much you weigh, and measure your blood pressure. When she measures your blood pressure, it will feel like the blood pressure cuff is giving you a big hug around your arm or leg.

You will be shown 2 buttons in your room. One is to call the nurse if you need something. The other one is for you to press if you feel your seizure or event coming. This will help us to not miss it.

You will be asked to change into the button-down shirt or zippered sweatshirt you brought with you. If you don't have one, it's OK because you can also wear a hospital shirt or gown.

EEG HOOK-UP

Now that you're in your button-down or zip-up, you are ready to go to the EEG hook-up room. The EEG technician will bring you there. It is only down the hall from your room, so it's not a long walk at all! Your parents can come with you into the room, and you can definitely bring something that makes you feel more comfortable, like a stuffed animal, blanket or pillow. Your job during the EEG is to stay still. Some things that can help you stay still for the EEG are watching a movie, being wrapped in a blanket or reading a book. There is a TV and VCR in the room for you to watch, but some kids also like to bring a DVD player or iPad with them from home if they have one.

Now it's time for me to tell you about the EEG. Did you know that your brain has a very important job? Your brain sends messages to your body to tell it what to do, like walk, talk, and play. The EEG wires, called electrodes, look at the way your brain sends these messages. The EEG can't tell what you're thinking or hear your thoughts—it can only see how your brain is sending messages to your body!

Some kids like to think of their brains like a video game controller. Video game controllers control the characters in a video game, the same way your brain controls how your body moves and works.

The first step of the EEG is that the technician will measure your head so that he or she can know exactly where each wire should go. As they measure, the technician will mark where the wires should go with a colored crayon. The tech might braid or move your hair to mark the right places. The crayon is meant to be used on skin and will come off when you shower. The technician will then start to put wires on your head using a special glue. Most kids need about 25 wires, so that the doctors can see as much as possible. The glue the technician uses to help the wires stay in the right place feels cold and wet and has a strong smell. This glue washes out in the shower.

Some kids who come to the hospital for an EEG have already had one before in their doctor's office. Those EEGS use paste that only stays on for a little while. When you stay overnight in the hospital for an EEG it needs to stay on for a few days, so they use stronger glue that takes longer to apply. If at any point you feel itchy, let your nurse know and she can show you ways to make it feel better.

To help the glue dry as quickly as possible, the technician will then use a small blow dryer. The air coming out will feel like a strong wind blowing and might be cold and noisy. Remember, your job is to stay still! Some kids watch a movie or pretend that they're a statue to help them stay still! Usually, the EEG hook up is done by the time you watch a few cartoons or read a few books.

When all of the wires are put on, the technician will make a hat out of gauze for you. The hat will cover your whole head and may even reach under your chin. This hat keeps the wires in the right place. It is important to keep the hat and wires in place or the tech will have to put them back on again. The wires come out of the hat and some kids think they

look like spaghetti hair! Other kids think they look like a long tail and like to imagine what animal with a tail they would be!

The last thing the technician needs to do to make sure you're all set up is put stickers on your chest. These stickers help the doctors measure how your heart is beating.

Once you're all set up, the technician will start to be able to see how your brain is sending messages to your body! Some kids might be asked to breathe really quickly. Some kids might have to watch a bright light flash.

POST-EEG

When the technician says you're all set, he or she will give you a backpack to carry the wires back to your room. In your room, the wires will be connected to a computer screen. On the computer screen, you will see squiggly lines called brain waves! Brain waves show what kind of messages your brain is sending throughout your body. You will be able to move around your bed, as long as you make sure you stay connected to the computer screen and are on camera. If you're able to see your picture on the computer screen, then the doctors and nurses can see you too. If you want to move to a different part of your room, you or your caregiver can let the nurse know and they will move the camera to follow you. There are also TVs at the nurses' station so that the nurses can make sure they are seeing everything they need to. The cameras will follow you when you're in bed or playing but not when you use the bathroom.

In your room, you can relax and have fun! If you want, you can bring some fun or favorite things from home to make you more comfortable. The child life specialist will also visit and bring you other fun activities.

Here is some important information for parents and caregivers to know about preparing for your visit...Thanks for listening kids, and we'll see you soon!

HELPFUL HINTS FOR PARENTS AND CAREGIVERS

Parent collaboration is really the key to success, both for the procedure and the entire hospitalization. Parents should know that the greatest comfort to their child is just having his or her parent there!

Some things to know before you come in for your visit:

- Most children are in the hospital for 2-5 days, though it depends on each child's individual circumstances.
- Before you arrive, your child's hair should be washed and dried. Please do not let your child arrive with any products or braids in their hair.
- As mentioned before, many children feel comforted when they have a familiar item from home, like a blanket or a stuffed animal. Definitely consider bringing these items!

- It is helpful if you bring button-down or zippered shirts or sweatshirts so that your child has an easier time getting in and out of it once he or she is hooked up to the monitoring equipment.
- You will probably want to bring an activity for yourself too, just like you do for your children!
- There is free Wi-Fi, TV and phone service. You can also access the GetWellNetwork, which includes movies, games, and the internet.
- Three meals are provided each day for parents: A breakfast cart in the morning, hot lunch in the Family Learning Place on the Lobby floor in the afternoon and sandwiches on the 6th floor in the evening. If you choose to bring food from outside, there is a fridge in the room. There are also two microwaves on the floor, one of which is designated for kosher food.
- Parking vouchers are available for parents or caregivers who are at the patient's bedside. Each patient is able to collect 2 vouchers per day for \$5 parking in the garage on 210th street.
- A parent or caregiver is not considered a visitor. All other visitors should come between visiting hours, which are between 12 and 8:30 PM. There is a sleeping couch at the patients' bedsides for one parent or caregiver to stay overnight with them.
- There is a bathroom in each patient room, however patients hooked up to electrode wires cannot shower and will instead have to be sponge bathed. There are showers on the unit that parents and caregivers can use.
- There might be some skin irritation at the site of the electrodes. It is important that the patients do not scratch. Any irritation will clear up soon after the electrodes are removed.

While your child is on the Epilepsy Monitoring Unit:

- You might be asked to tell your story, issues and concerns many times. This is because each team member wants to hear it from the family and examine it from their own perspective.
- You will be shown 2 buttons once you're in your room: one to call the nurse if you need something, and one for when a seizure or the atypical episode occurs. While we ask children to press the buttons, sometimes their seizure or event spreads so quickly that we also need your help.
- -The morning after admission, each child will need to get a blood draw. The hospital staff is trained to do everything they can to make the patient as comfortable as possible.
- Every morning, the patient's head and wires will be checked to make sure everything is still in the right place. Sometimes the tech will need to re-secure some electrodes that have become loose overnight.
- Each morning, the epilepsy team will meet with you to discuss what they saw the previous day and their plan for the current day, as well as ask you about any concerns.

When you're ready to go!

- When it's time for the child to be discharged to go home, the electrodes will be removed. You will be given an oil to rub through your child's hair to loosen up the electrodes before taking a shower to wash out any remaining glue.

All of the staff in the Epilepsy Monitoring Unit looks forward to meeting you and providing excellent care to your child and family!

Appendix B:

“Un Viaje a la Unidad de Monitoreo de Epilepsia”

REGISTRO

Tu vienes para permanecer en el hospital para que los médicos puedan tener una mejor idea de lo que le está sucediendo a tu cerebro. Te harán un examen que se llama un EEG - la cual explicamos mas adelante.

A tu llegada al hospital lo primero es registrarte.

EL HOSPITAL PRINCIPAL

Al terminar con tu registro debes venir al edificio del hospital de los niños.

LA UNIDAD DE MONITOREO DE EPILEPSIA

Tomarás el ascensor al 6° piso en donde se encuentra la Unidad de Monitoreo de Epilepsia. Al salir del ascensor te dirigirás a la secretaria de la unidad, quien tiene muchos trabajos importantes, y ella te dirá a ti y a tu familia a donde dirigirse. Cuando estés en el 6° piso, te darán una pulsera con tu nombre y otra información importante. Tendrás que mantener esta pulsera todo el tiempo que estés en el hospital para que todas personas sepan quien eres.

LA SALA DE ESPERA

Tu y tus padres o cuidadores pasarán a una sala de espera para hablar con una enfermera, un técnico de EEG, el asistente medico o doctor antes de ir a tu habitación. Es un buen idea de traer una picadera y algo con que entretenerte.

Cuando conozcas a los doctores, asistentes médicos y enfermeras te van a preguntar que medicamentos tomas normalmente en casa y sobre las convulsiones que tienes para que el personal del hospital esté mejor preparado para ellos.

Tu también recibirás un examen medico y neurológico completo para que los doctores conozcan que sano estás.

CONOCES LOS EMPLEADOS DEL HOSPITAL

Estas son algunas de las personas que trabajaran en el equipo para atenderte a ti y a tu familia mientras estés en el hospital.

Médicos Tratantes: Cada mes un medico tratante diferente estará encargado de trabajar con los pacientes en la Unidad de Monitoreo de Epilepsia. El doctor pasará todos los días para ver como te encuentras. El o ella le comunicará al resto del equipo médico de lo que están viendo cada día.

Asistente Médico: El Asistente Medico trabaja cerca con tu doctor y enfermeras para ayudar a crear un plan de cuido diario para ti.

Enfermeras: Las enfermeras estarán visitándote durante el día y asegurándose que estés cómodo. Van a tomarte la temperatura y la presión arterial y te darán los medicamentos que tomas.

En algún momento durante tu estancia en le hospital conocerás a un especialista en la vida infantil. El especialista en la vida infantil te puede explicar cosas del hospital, ayudarte durante tu conexión con la EEG y también te puede traer varias actividades divertidas para hacer mientras estás en el hospital.

Técnico de EEG: El técnico de EEG es una persona que está capacitado para prepararte para tu EEG.

Trabajadores Sociales: El trabajador social vendrá a conocer a tu familia y hacer preguntas sobre tu vida para ayudarles a crear un plan para cuando salgas del hospital.

Personal de Alimentos: Un grupo de personas que te traen tu desayuno, almuerzo y cena mientras te encuentras en el hospital.

Servicios Ambientales: Posiblemente veas a alguien de Servicios Ambientales cuyo trabajo es asegurarse de que las habitaciones y el hospital siempre se encuentren limpios.

TU HABITACIÓN

Ahora vamos a ver tu habitación. Tu mamá, o papá o cuidador se quedará contigo mientras tu estás en el hospital, incluso mientras tu duermes. Esto es tanto para que te sientas más cómodo y también para que nos ayude registro cuando tu estas teniendo un convulsión o evento. A lo mejor tu vas a compartir con alguien.

Tu enfermera entrará a la habitación para conocerte y para tomarte lo que se conoce como tu “signos vitales”. Esto quiere decir que te tomará la temperatura con un termómetro, verá cuanto pesas y medirá tu presión arterial. Cuando mida tu presión arterial sentirás como que la pulsera que mide la presión te está dando un fuerte abrazo alrededor de tu brazo o pierna.

Te enseñaremos dos botones en tu habitación. Uno es para llamar la enfermera si necesitas algo. El otro botón es para tu presionar si tu sientes que tu evento de convulsión esta viniendo. Esto podría ayudarnos para no perdérselo y estar preparados.

Tu tendrás que cambiarte a la camisa de botones o sudadera de cierre que trajiste de tu casa. Si no tienes una, está bien, porque también puedes ponerte la camisola del hospital.

EL CONEXIÓN DEL EEG

Ahora que ya estas con tu camisa de botones o sudadera de cierre estás listo para ir al cuarto de conexión del EEG. El técnico del EEG vendrá por ti para llevarte. Se encuentra

a unos cuantos pasos de tu habitación así que no es una larga caminata. Tus padres te pueden acompañar al cuarto y definitivamente puedes traer contigo algo que te conforte como tu muñeco de peluche, frazada o almohada favorita. Tu trabajo durante el EEG es quedarte tranquilo. Alguna de las cosas que te pueden ayudar a quedarte tranquilo son ver una película, estar envuelto en tu frazada o leyendo un libro. Hay una televisión y videograbadora en el cuarto para que la puedan ver, pero algunos niños prefieren traer un reproductor de DVDs o iPad, si es que tienes uno.

Ahora te voy a contar que es el EEG (Electroencefalografía). ¿Sabías que tu cerebro tiene un trabajo muy importante? Tu cerebro le manda mensajes a tu cuerpo para avisarle que es lo que debe hacer, como caminar, hablar y jugar. Los cables del EEG, llamados electrodos, ven la forma en la que tu cerebro manda esos mensajes. El EEG no puede ver lo que estás pensando o escuchar sus pensamientos, ¡sólo puede ver como tu cerebro está enviando mensajes a tu cuerpo!

A algunos niños les gusta pensar que su cerebro es como el control de un videojuego. Los controles de los videojuegos controlan a las personajes del videojuego de la misma manera que tu cerebro controla como tu cuerpo se mueve y funciona.

El primer paso del EEG es que el técnico mide tu cabeza para saber exactamente a donde va cada cable. Al irlo midiendo, el técnico marcará con crayones de colores en donde deben de ir. Posiblemente el técnico te moverá el cabello o hará trenzas para poder marcar el lugar exacto. El crayón es especial para la piel y se quitara en cuanto te bañes.

El técnico empezara poniendo los cables en tu cabeza usando un pegamento especial. La mayoría de los niños necesitan aproximadamente 25 cables, para que los doctores vean lo mas posible. El pegamento que usan los técnicos ayuda a que los cables se queden donde deben estar. Al colocarlos se siente frío y húmedo, y tiene un olor muy fuerte. También se caen cuando te bañes.

Alguno niños que vienen al hospital para un EEG ya han tenido uno antes en la oficina de su medico. Esos exámenes usan pasta que solo permanece para un breve periodo de tiempo. Cuando te quedas en el hospital, el EEG necesita mantenerse para unos días, así que utilizan un pegamento mas fuerte de que toma más tiempo para aplicar. Si en algún momento se siente con comezón, dígame a su enfermera y ella le puede mostrar maneras de hacer que se sienta mejor.

Para ayudar a que el pegamento se seque rápidamente, el técnico usara una secadora pequeña. El aire que sale se sentirá como un viento fuerte y puede ser frío y ruidoso. ¡Recuerda, tu trabajo es quedarte quieto! Algunos niños ven una película o pretenden que son una estatua para ayudarlos a mantenerse quietos. Normalmente el EEG se hace mientras ves unos cuantos episodios de caricaturas o lees unos libros.

Cuando todos los cables estén colocados, el técnico te hará un sombrero de gasa para cubrir toda la cabeza y puede llegar a cubrirtte hasta tu barbilla. Este sombrero ayuda a mantener todos los cables en el lugar correcto. Es importante mantener el sombrero y los

cables en su lugar para que el técnico no tenga que pegarlos otra vez. Los cables saldrán del sombrero y se verán como una larga cola. A algunos niños les gusta adivinar cual animalito con cola son.

La última cosa que el técnico tiene que hacer es poner unas calcomanías en tu pecho que ayudan a los doctores a medir como esta latiendo tu corazón

Cuando este todo listo, el técnico empezara a poder ver como tu cerebro está mandando mensajes a tu cuerpo. Posiblemente se les pedirá a algunos niños que respiren muy rápido, posiblemente a otros niños se les pedirá que vean una luz muy brillante.

DESPUÉS DEL EEG

Cuando el técnico te diga que estás listo, te darán una mochila para llevarse todos los cables de regreso a tu habitación. En tu habitación, conectaran todos los cables a una pantalla de computadora. En la pantalla, se podrán ver unas líneas onduladas, que se les conoce como ondas cerebrales. Las ondas cerebrales muestran que tipos de mensajes el cerebro está enviando a todo el cuerpo. Te podrás mover alrededor de la cama, siempre y cuando te asegures de mantenerte conectado a la pantalla de la computadora y que tu estas en cámara. Si tu estás disponible para mirar tu imagen en la pantalla de computadora, los doctores y las enfermeras pueden verte a ti también. Si tu quieres mover a una parta diferente de tu cuarto, tu o tu cuidador puede dejar la enfermera saber y ella puede mover la cámara para seguirte aquí . También habrá cámaras de video en tu habitación para que los doctores te vean y ligen lo que está haciendo tu cuerpo con lo que está haciendo tu cerebro. Hay televisiones en las estaciones de enfermeras para asegurarse que vean todo lo que necesitan ver. Las cámaras te seguirán mientras estas en la cama o jugando, pero no cuando utilices el baño.

En tu habitación podrás relajarte y divertirte! Puedes traer cosas divertidas o tus cosas favoritas de su casa si deseas, para que te sientas mas cómodo. El especialista en vida infantil también te visitará y traerá otras actividades divertidas.

Aquí tenemos un poco de información importante para ellos acerca de la preparación de tu visita....¡Niños, muchas gracias por su atención y nos vemos pronto!

CONSEJOS ÚTILES PARA LOS PADRES Y CUIDADORES

La colaboración de los padres es realmente la clave para el éxito, tanto para el procedimiento como para la hospitalización. Los padres deben saber que la mayor tranquilidad que le pueden dar a su hijo o hija es simplemente el estar ahí con ellos.

Algunas cosas que debes de saber antes de tu visita:

- La mayoría de los niños están en el hospital de 2 a 5 días, aunque esto depende de las circunstancias individuales de cada niño.

- Antes de su llegada, el cabello de su hijo o hija debería estar lavado y seco. Por favor no permitan que su hijo o hija lleguen con ningún producto (goma de pelo, spray, etc.) o trenzas.
- Como se mencionó anteriormente, muchos niños se sienten mas confortables si traen de la casa algún artículo familiar como su peluche favorito, o frazada (cobija). Definitivamente considere traerlos.
- Es útil traer camisas con botones o sudaderas con cierre para facilitar todos que su hijo o hija le sea mas fácil ponerse y quitarse para cuando estén conectados al equipo de monitoreo.
- Probablemente usted querrá traer alguna actividad para hacer, de igual forma que para sus hijos, como libros, revistas, tejidos, etc.. Hay conexión de Wi-Fi gratuita, TV y teléfono. También pueden hacer uso del “GetWellNetwork”, que incluye películas, juegos e Internet.
- Diariamente le ofrecerán tres comidas a los padres: un carro de desayuno en la mañana, almuerzo caliente en el “Family Learning Place” en el Lobby o planta baja en la tarde y sándwiches en el 6º piso para la cena. Si decide traer comida de afuera, hay un refrigerador en la habitación y dos hornos de microondas en el piso, uno de los cuales es designado para la comida Kosher.
- A los padres o cuidadores más cercanos al paciente se les otorgaran vales para el estacionamiento ubicado en la calle 210. Cada paciente podrá obtener 2 vales de estacionamiento por día por \$5.00 .
- Los padres o cuidadores no serán considerados como visitantes. Todos los demás deberán de visitar durante las horas de –Un padre o cuidador no es considerado visita. Todas otras personas pueden venir mientras las horas de visita que son de 12:00-8:30pm. Junto a la cama del paciente hay un sofá-cama para uno de los padres o cuidadores se quede durante la noche con el paciente.
- En cada habitación hay una baño pero los pacientes que se encuentren conectados no podrán bañarse, solamente podrán tener un baño de esponja. Hay duchas en el piso que los padres y cuidadores pueden usar.
- Puede haber algún tipo de irritación en la piel donde se encuentran los electrodos. Es importante que los pacientes no se rasquen. La irritación se quitará en cuanto se retiren los electrodos.

Mientras su hijo o hija se encuentra en la Unidad de Monitoreo de Epilepsia:

- Es posible que le pregunten contar varias veces todo su historial, los problemas y sus preocupaciones. Esto es debido a que cada miembro del equipo médico quiere escucharlo directamente de la familia y examinar la situación desde su propia perspectiva.
- Se le mostraran 2 botones cuando estén en el cuarto: el primero es para llamar a la enfermera si necesitan algo y otro cuando tenga un ataque o episodio atípico. Nosotros les pedimos a los niños que presionen los botones, pero algunas veces sus episodios o sus síntomas son tan rápido que nosotros también necesitamos su ayuda.
- La mañana siguiente de su admisión al hospital, se requiere sacarle una muestra de sangre al paciente. El personal del hospital está entrenado para que el paciente esté lo más cómodo posible.

- Todas las mañanas, se revisara la cabeza del paciente y los cables para asegurarse que todo permanece en el lugar correcto. En ocasiones el técnico necesitará volver a pegar algunos de los electrodos que se hayan aflojado durante la noche.
- Cada mañana el equipo de epilepsia se reunirá con la familia para discutir que han visto el día anterior, el plan para este día también como preguntarte si tienes algunos pensamientos.

Cuando esté listo para regresar a casa:

- Cuando llegue el momento para que el niño sea dado de alta y regresar a casa, se le removerán los electrodos. Se le dará un aceite para frotar en el cabello que aflojará los electrodos antes de bañarse y quitar el pegamento restante.

Todo el personal de la Unidad de Monitoreo de Epilepsia está esperando conocerlos y brindarles un excelente cuido a su hijo y a su familia.

Appendix C:

A Trip to the Epilepsy Monitoring Unit



Come to the hospital.



Go to the 6th floor.



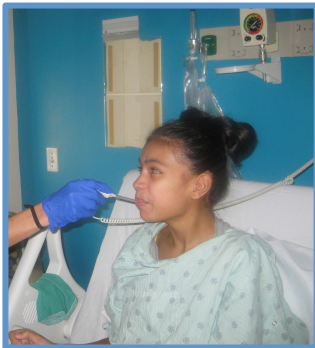
Wait in the lounge area.



Meet the staff.



Go to your hospital room.



Meet the nurse. She will measure your temperature, blood pressure and check how much you weigh.



Get a check-up of your whole body.



Change your shirt.



Meet the EEG technician and go with him or her to the treatment room.



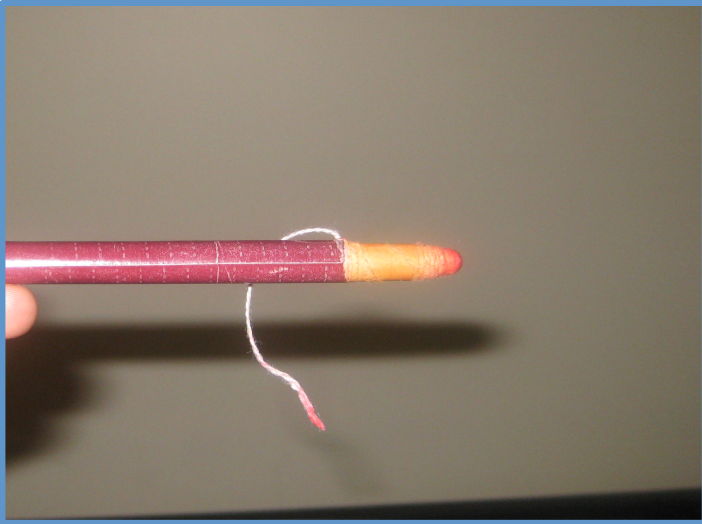
You can watch a TV show or a movie.



Lay down on the bed.



Your head is measured.



A soft crayon is used to mark the right spot.



**Wires are put on with glue.
The glue feels cold and you might be able to smell it.**



Air blows to dry the glue.
Air blowing feels like a strong wind. It might be cold and noisy.



More glue and more air!



Try and stay as still as you can.



Your head is covered with cloth to make a hat.



Stickers are put on your chest.



Go back to your room.



Don't touch the wires or the hat. Try not to scratch.



Play and have fun!

Appendix D:

Un Viaje a la Unidad de Monitoreo de Epilepsia



Ven al hospital.



Ve al sexto piso.



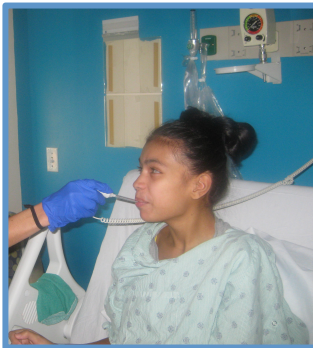
Espera en el salón.



Conoces los empleados del hospital.



Ve a tu habitación.



Conoces a la enfermera. Ella medirá tu temperatura, tu presión arterial y verificará cuanto pesas.



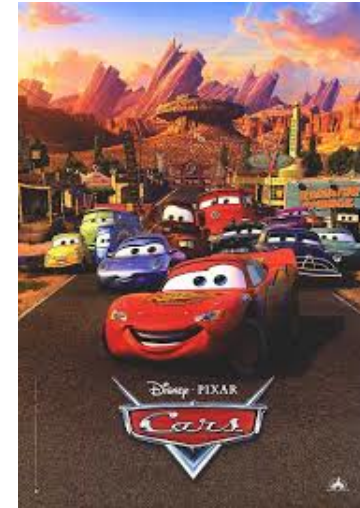
Tener un chequeo de rutina de todo su cuerpo.



Cámbiate la camisa.



Conoces al técnico EEG y ve con el o ella al sala de tratamiento.



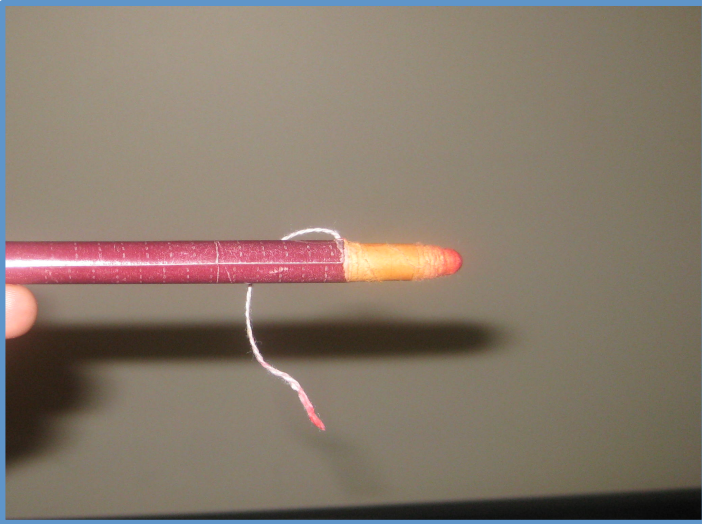
Tu puedes ver un programa de televisión o una película.



Acuéstate en la cama.



Tu cabeza va ser medida.



Un crayón suave se usa para marcar los lugares correctos.



**Alambres están aplicados con pegamento.
El pegamento se siente frío y es posible que tu puedas olerlo.**



Aire sopla para secar el pegamento. El movimiento del aire se siente como un viento fuerte. Puede ser frío y ruidoso.



¡Más pegamento y más aire!



Tratas lo mas que puedas de quedarte tranquilo.



Su cabeza está cubierta con tela para hacer un sombrero.



Etiquetas están puestas en tu pecho.



Vuelve a tu habitación.

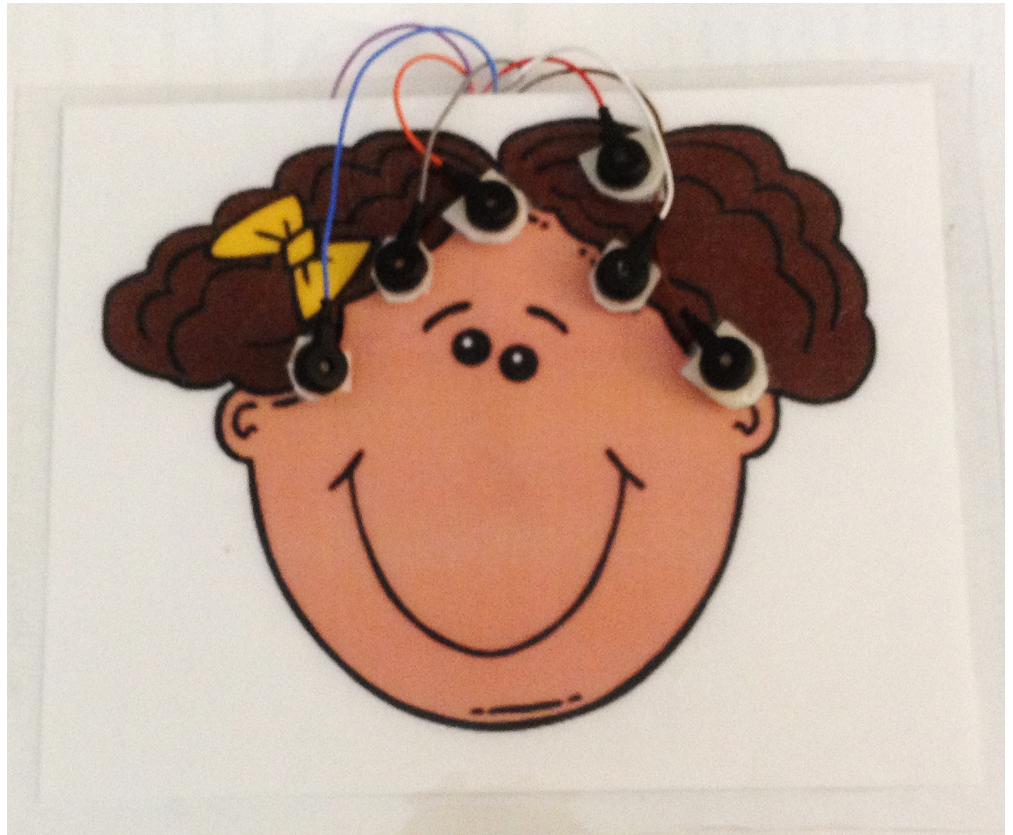


**No te puedes tocar los alambres o el sombrero.
Trata de no rascarte.**



¡Juega y que te diviertas!

Appendix E:



Appendix F:

Consent and Release Letter

Dear Parent/Guardian,

My name is Peyton Katz and I am a graduate student in Child Life at Bank Street College of Education in New York. For my Master's thesis I will be creating materials to help prepare children and families for their visit to the hospital's Epilepsy Monitoring Unit. One of the tools I will be designing is a preparation book for patients and their caregivers to learn about the unit and the EEG hook-up process. With your permission, I would like to include photographs of your child at significant points of the hospitalization in order to help other children with their own admissions in the future.

The final project will be utilized at the Children's Hospital at Montefiore and may serve as a model program for other hospitals interested in establishing programs to prepare children and their families for admissions requiring EEG monitoring. The thesis will also be shared as a PDF with the Bank Street community in a password-protected searchable database and may also be submitted as a PDF to the Bank Street Library where it would be catalogued as part of the Library collection and entered into an international database for wider circulation. The material may also be included in professional presentations and publications.

Please sign the attached form to indicate that you grant permission for your child's photograph to be used for the purpose of this project.

Thank you for your consideration.

Sincerely,

Peyton Katz

Consent and Release Form

Consent and Release Form for Parent or Guardian

I am the parent/guardian of _____.

I give my permission to Peyton Katz to use (check all that you are consenting to):

_____ Photo documentation of my child

_____ Video documentation of my child

_____ Audio documentation of my child

I understand that my child's name and the name of the hospital and community will be protected by pseudonyms in the actual thesis as well as in any professional talks and publications. I grant permission Peyton Katz to use the above noted documentation of my child in the thesis document and in professional presentations and publications.

I have read this release form and agree to its terms knowingly and voluntarily.

Parent/guardian's name _____ Date _____

please print

Parent/guardian's signature _____ Date _____

signature